

The Internet as a Source of Health Information: Experiences of Cancer Survivors and Caregivers With Healthcare Providers

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Data from the Health Information National Trends Survey examining health and cancer information seeking in the United States revealed divergent patterns between actual and preferred sources of health information during cancer survivorship (Hesse, Arora, Beckjord, & Finney Rutten, 2008; Hesse et al., 2005). Although cancer survivors reported their healthcare provider as their preferred source, the Internet was the first and most common source of health information. Little is known about how the Internet as a source of health information and resources is changing healthcare relationships in cancer survivorship.

Dissatisfaction with information and communication during clinical encounters with healthcare professionals has propelled cancer survivors to search for health information and resources on the Internet (Chen & Siu, 2001; Pereira, Koski, Hanson, Bruera, & Mackey, 2000; Sharf, 1997; Ziebland, 2004; Ziebland et al., 2004). Factors contributing to dissatisfaction and demand for health information include insufficient time spent on communication during the clinical encounter and healthcare providers' inability to keep up with the most current information and advances in cancer care (Anderson, Rainey, & Eysenbach, 2003).

Survivor empowerment emerges as a major construct in healthcare relationships in the context of Internet information seeking (Broom, 2005b; Dickerson, Boehmke, Ogle, & Brown, 2006; Pitts, 2004; Sharf, 1997; Ziebland et al., 2004). Well-informed survivors report increased confidence in their interactions with healthcare providers and greater engagement in care decisions as evidenced by asking more questions, requesting tests and treatments, and being better prepared for discussions (Bass et al., 2006; Broom, 2005b; Dickerson et al., 2006; Newnham et al., 2006). Empowering behaviors such as bringing information from online searches to the clinical encounter and questioning healthcare providers have been perceived by both survivors and healthcare providers as challenging the boundaries of medical expertise (Broom, 2005b;

Purpose/Objectives: To describe the experiences of cancer survivors and caregivers with healthcare providers in the context of the Internet as a source of health information.

Research Approach: Qualitative description.

Setting: Online cancer communities hosted by the Association of Cancer Online Resources.

Participants: Purposive sample of 488 cancer survivors, with varying cancer types and survivorship stages, and caregivers.

Methodologic Approach: Secondary data analysis using Krippendorff's thematic clustering technique of qualitative content analysis.

Main Research Variables: Survivorship, healthcare relationships, and the Internet.

Findings: Disenchantment with healthcare relationships was associated with failed expectations related to evidence-based practice, clinical expertise, informational support, and therapeutic interpersonal communication. Survivors and caregivers exercised power in healthcare relationships through collaboration, direct confrontation, becoming expert, and endorsement to influence and control care decisions.

Conclusions: Disenchantment propelled cancer survivors and caregivers to search the Internet for health information and resources. Conversely, Internet information-seeking precipitated the experience of disenchantment. Through online health information and resources, concealed failures in healthcare relationships were revealed and cancer survivors and caregivers were empowered to influence and control care decisions.

Interpretation: The findings highlight failures in cancer survivorship care and underscore the importance of novel interdisciplinary programs and models of care that support evidence-informed decision making, self-management, and improved quality of life. Healthcare professionals need to receive education on survivors' use of the Internet as a source of health information and its impact on healthcare relationships. Future research should include studies examining the relationship between disenchantment and survivorship outcomes.

Brotherton, Clarke, & Quine, 2002; Dickerson et al., 2006; Pitts, 2004; Sharf, 1997; Ziebland et al., 2004).

Current evidence suggests a paradoxical influence of the Internet on healthcare relationships. Several studies

(Bass et al., 2006; Brotherton et al., 2002; Chen & Siu, 2001; Newnham et al., 2006; Norum, Grev, Moen, Balteskard, & Holthe, 2003; Pereira et al., 2000; Shaw et al., 2007) suggested that the use of the Internet enhances healthcare relationships for cancer survivors. However, the perceptions of healthcare providers have been mixed, with reports of positive, negative, and neutral effects of the Internet on healthcare relationships (Broom, 2005a; Chen & Siu, 2001; Helft, Hlubocky, & Daugherty, 2003; Newnham et al., 2005). Helft et al. (2003) suggested that the Internet contributed to increasing survivors' confusion, anxiety, and false hopes, resulting in additional time spent in clinical encounters.

Research is needed to more fully understand the impact of Internet health information on the delivery of quality cancer care (Huang & Penson, 2008). The purpose of this qualitative, descriptive study was to describe the experiences of cancer survivors and caregivers with healthcare providers in the context of the Internet as a source of health information and to advance knowledge about how the Internet is changing healthcare relationships in cancer survivorship.

Methods

The current study is a secondary analysis of a qualitative data set from the 2006 Pew Internet and American Life Project, *E-patients With a Disability or Chronic Disease* (Fox, 2007). In the original study, Fox conducted a cross-sectional, random digit-dial telephone survey (N = 2,928) and found that Internet users with a chronic condition (n = 268) were significantly more likely to report an impact on treatment decisions and relationships with healthcare providers than Internet users without a reported chronic condition. In addition to this telephone survey, an online questionnaire was administered to participants of cancer-related communities hosted by the Association of Cancer Online Resources (ACOR) (www.acor.org), a comprehensive resource for electronic cancer support groups. A total of 1,680 participants responded to the online survey, with 488 participants (29%) completing an open-ended question about their personal experiences with online resources. The original open-ended question asked, "Is there a particular incident or story from your own experiences online, about a particular site, or about someone you contacted through the Internet that makes an important point about online health resources?" These data were not fully analyzed in the original study.

A qualitative, descriptive research design was used to describe the experiences of cancer survivors and caregivers with healthcare providers. Qualitative content analysis was selected as an appropriate research method for qualitative description (Sandelowski, 2000). In addition, Krippendorff's (1980, 2004) thematic clustering technique of qualitative content analysis was used to discover recurring patterns or themes in the data. The re-

search question asked: What are the experiences of cancer survivors and caregivers with healthcare providers in the context of online health information and resources?

Sample, Recruitment, and Data Collection

This Internet sample (n = 488) of cancer survivors and caregivers self-selected to participate in the original study and share their personal story. Study participants, recruited from announcements posted on the ACOR mailing lists, were members of one or more cancer-related online communities (Fox, 2007). Data collection occurred over a one-week period in November 2006. Informed consent was obtained in the original study. The principal investigator of the original study agreed to this secondary analysis. The current study was approved by the New York University Committee on Activities Involving Human Subjects. To protect the privacy and confidentiality of the study participants, all identifying information was cleared from the data set prior to data analysis.

Content Analysis

Purposive sampling was used to identify a total of 182 thematic units of analysis relevant to answering the research question. Each thematic unit of analysis was coded by the respondent and the online cancer community from which it was collected. Thematic units of analysis were analyzed by grouping similar qualities or attributes, resulting in the reduction of data into clusters until all data were merged. Iterative clustering steps were followed and documented in the form of a dendrogram, a tree-like diagram that represents the merging of thematic units of analysis (Krippendorff, 1980, 2004) (see Figure 1).

Study Rigor

The rigor or trustworthiness of the current study was established by addressing five criteria: credibility, dependability, confirmability, transferability (Lincoln & Guba, 1985), and authenticity (Guba & Lincoln, 2005). Credibility or confidence in the findings was established by maintaining a reflexive journal for self-reflection. Reflections triggered by the text readings were documented in journal entries, which allowed the themes to emerge from the text rather than from the subjectivities or biases of the researcher. Dependability or reliability of study findings was established by maintaining an audit trail of all procedural steps and methodologic decisions. The dendrogram was used to document the clustering procedure and served as an audit trail. Confirmability or objectivity of the findings was established by using peer debriefing and an external auditor with expertise in Krippendorff's thematic clustering technique. To establish authenticity or fairness that all participants' voices were depicted in the findings (Guba & Lincoln, 2005), all relevant sampling units including negative or divergent data were clustered. The authenticity of the

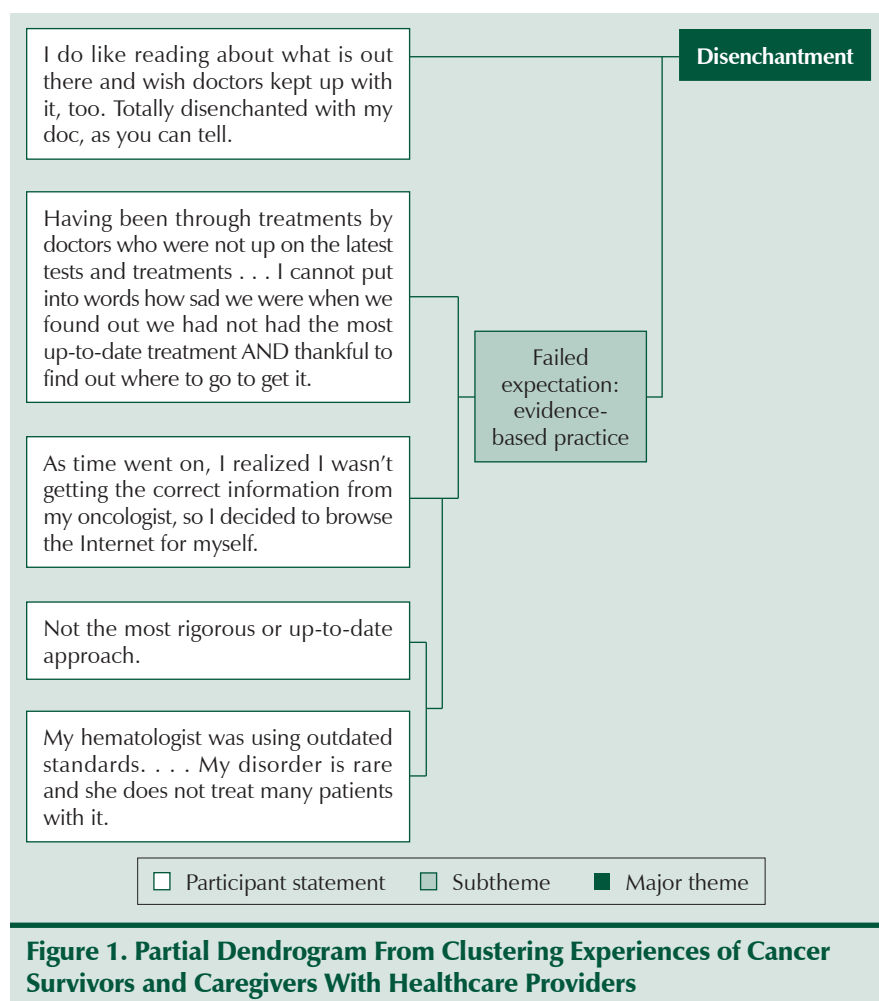


Figure 1. Partial Dendrogram From Clustering Experiences of Cancer Survivors and Caregivers With Healthcare Providers

current study emerged in the participants' powerful written statements, which were used to support the researcher's interpretations.

Results

Clustering the experiences of cancer survivors and caregivers with healthcare providers revealed two recurring themes: *disenchantment* and *exercising power*. The themes emerged from the descriptive data written by participants from 35 cancer-related online communities (to access the communities, visit www.acor.org/mlists/mlists.html). The sample of participants had varying types of cancer and stages of survivorship. Participants from the United States, the United Kingdom, Australia, and Canada shared their experiences with healthcare providers in the context of online health information and resources.

Disenchantment

Disenchantment, a profound emotional experience characterized by sadness, disappointment, dissatisfaction, hopelessness, frustration, anger, and distrust, was

associated with failed expectations related to evidence-based practice, clinical expertise, informational support, and therapeutic interpersonal communication.

Evidence-based practice: Several participants shared stories about not receiving the most up-to-date cancer information. Cancer survivors and caregivers learned about the latest cancer treatments and were able to access the best available research. A survivor shared, "My daughter and a couple of friends printed information off the Internet about carcinoid cancer. As time went on, I realized I wasn't getting the correct information from my oncologist, so I decided to browse the Internet for myself." A caregiver wrote, "I cannot put into words how sad we were when we found out we had not had the most up-to-date treatments AND thankful to find out where to go to get it." A survivor with chronic lymphocytic leukemia commented, "I do like reading about what is out there and wish doctors kept up with it, too. Totally disenchanted with my doc, as you can tell."

Clinical expertise: Participants shared stories of diagnostic failures in which symptoms had been undiagnosed, incorrectly diagnosed, or dismissed by their healthcare provider. Survivors presenting with rare cancers or unusual side effects encountered healthcare providers with a lack of clinical expertise in treating their disease and, consequently, turned to the Internet. A survivor with carcinoid cancer stated,

I have a rare disease. The first three physicians I saw after diagnosis had never before had a patient with this disease. I immediately joined an online support group and had personal e-mail contact with persons who answered my questions, helped reduce my fear, and helped me come to terms with my diagnosis.

Another survivor reported,

After describing my symptoms to the members of [my online community], I learned via their feedback that I had been misdiagnosed and that my doctor really didn't have enough experience to manage my case. Changing doctors was the result and probably a life-saving decision.

Several patients turned to the Internet to diagnose themselves. One survivor with acute myelogenous leukemia shared,

I diagnosed myself using online resources. I had been to the dentist twice with bleeding/swollen gums, and had been to the doctor once [with] various other symptoms (bruising, persistent cough, a cut that wouldn't heal, etc.). Neither one of these healthcare providers connected the dots or even suggested a blood test. Several days later when my symptoms worsened, I went online to a cancer Web site and found a description of what I was experiencing.

Informational support: Participants experienced a lack of informational support from healthcare providers, captured by this statement from a survivor with testicular cancer: "I knew only the little that my urologist told me." Several participants were perplexed about their healthcare provider either not knowing or withholding important information. A survivor with pancreatic cancer reported,

I was experiencing continued weight loss, along with diarrhea, after my treatments were begun. Someone else posted on the [online community] that they were using enzymes with their meals and that it had helped a great deal. I hadn't heard of this before and my oncologist never mentioned it to me, either. I asked my doctor for a prescription and it has helped me significantly. I often wonder why my doctor never suggested it to me.

Survivors experienced a lack of informational support related to procedures and were better prepared after seeking information on the Internet. One survivor with bladder cancer stated, "[I] faced surgeries with a very good idea of what was to happen, sure did not know this prior to first surgery." Another survivor found reading blogs written by other patients who had experienced a procedure to be helpful and wrote, "I could better relate to their experience and it helped to know what to expect from a physical and emotional perspective."

Survivors required practical information to help them manage their illness at home and found help from their online communities. One survivor with bladder cancer shared her personal story about self-catheterization.

I was terrified of self cathing when it became clear that I was hypercontinent. Several women online assured me that it was doable and even described how they self cath, e.g., that I would need a small mirror with a hinge, that it would have to fit between the seat of the toilet and the bowl. I did not get this information from the doctor even though the hospital had a "training" session. The session showed me where my body parts were, but gave me no practical information that I needed four months later. My online helpers really saved me!

Therapeutic interpersonal communication: Cancer survivors and caregivers experienced failures in therapeutic communication with their healthcare providers. One survivor said, "The doctor, while an excellent surgeon,

is not a good communicator." Another survivor with testicular cancer recognized that "medical professionals are in increasing short supply, and have less and less time to really communicate with patients." Participants experienced some healthcare providers who were unwilling to discuss health information found on the Internet. One survivor with carcinoid cancer wrote, "Having researched and learned a great deal about my specific cancer, I find that most doctors would rather the ignorant patient. This simply frustrates the patient who is searching for answers and good treatment." A caregiver found a number of pertinent medical journal articles and noted, "Our local oncologist did not want to discuss them with me, but the experts we saw were using these very articles to make their decisions about treatment recommendations."

Several survivors and caregivers perceived healthcare providers as "unconcerned" about their symptoms and consequently turned to the Internet. One caregiver shared, "When my daughter first had symptoms, my pediatrician wasn't very concerned, but I was. I automatically went to the Internet and began researching." A survivor said,

I contacted [a member of my online community] at ACOR for help when my physicians didn't seem to want to listen about the late effects of radiation and chemo. Her information on that list/forum probably saved my life. It showed me that the symptoms I was experiencing [were] not "all in my head."

Stories were shared about needing "emotional support" and turning to online communities. One caregiver dealing with esophageal cancer wrote,

It's a rare cancer and we have no friends or acquaintances who have had it, so connecting online is the ONLY way we could find emotional and medical support outside of the few minutes our doctor can spare every few weeks.

A caregiver recalled,

I posted a message on the [online community] when my husband was diagnosed—a cry for help because he was getting the medical treatment that he needed, but I didn't think that either of us were receiving the mental help we needed.

Exercising Power

Exercising power in healthcare relationships was manifested by patterns of collaboration, confrontation, becoming expert, and endorsement. Participants exercised their own power or will to influence and control care decisions during survivorship.

Collaboration: Survivors and caregivers exercised power through collaboration, a sharing of power and responsibility with their healthcare providers in making healthcare decisions. A survivor shared, "I am the only person in our small town with [chronic lymphocytic

leukemia] and my oncologist was grateful to have the help from an online group. He was . . . a team player all around." One survivor with sarcoma was "grateful for the Internet and the ability of patients to connect with one another and become empowered and teach their doctors to allow them to be members of the team." Collaborative healthcare providers were receptive to survivors and caregivers bringing knowledge and information gathered from the Internet to the clinical encounter. For example, one survivor shared,

Our [general practitioner] was unfamiliar with amyloidosis. We printed the information off of the amyloidosis support network Web site and gave it to him PRIOR to our office visit to discuss pathology results. He was very receptive to learning about this disease and thanked us for giving him the information to peruse prior to our visit.

Participants provided examples of collaboration resulting in changes in their plan of care. A caregiver illustrated, "We shared info from an Internet source with our child's neurologist that resulted in his contacting [the] author of a study at [hospital name withheld], which in turn led to a change in medication for our child."

Confrontation: Participants exercised power through direct confrontation with their healthcare providers, which included behaviors such as questioning, persuasion, and coercion. Armed with the "right questions to ask," survivors and caregivers challenged healthcare providers. Participants influenced their care and treatment plan by exerting persuasive power in their relationship with healthcare providers. One survivor shared,

The Internet allowed me to track down a couple of journal articles relating to this [off-label] use, which helped persuade my doctor . . . to try it, and I was able to send an e-mail to the lead author of one article to get an update on dosage.

Another survivor with myeloproliferative disorder explained, "I persuaded my [doctor] to start me off at a dosage level suggested by several members of our support group. This was a major benefit to me in that I avoided nearly all of the adverse effects." Participants exerted coercive power in their relationship with healthcare providers. Many were able to "insist" on treatments, "demand" procedures, and "push" for care. A parent concluded, "Thanks to the Internet, I pushed for what my daughter needed." Another parent shared,

[Our son] became so underweight that we thought we might lose him. Several [online community members] recommended a drug which helped them post-transplant. We had to push the medics here to give it to [him], after that his health improved very quickly.

Becoming expert: Participants exercised power by becoming knowledgeable about treatments, medications,

side effects, complications, and clinical trials. Several participants were embraced by their healthcare provider as being an expert in their cancer. One survivor shared,

I have a rare type of ovarian cancer, which means that few doctors have a real expertise in it. But being a part of an online community with over 1,200 members, going back more than 10 years, means that I have access to a large number of other survivors of this type of cancer. My doctor has laughed and said: "You are becoming more expert on clear cell ovarian cancer than most oncologists!"

Another survivor with ovarian cancer reported,

When I was in pre-op for my staging surgery . . . my gyn-onc had a surgical resident with him. The resident began citing inaccurate information, and I corrected him, in the presence of my gyn-onc, his supervisor. Before the resident could respond, my doctor walked over, hugged me so hard it hurt, and told him to pay attention, that I belonged to a group of women who know more about their cancer than many of their doctors do, and there were more of us out there.

Cancer information verified through online resources influenced survivors' choices and care decisions. Participants changed healthcare providers as a result of conflicting information. A survivor with carcinoid stated,

I was able to get information about treatment of carcinoid that conflicted with what my oncologist said—so I sought several specialists' opinions and they all agreed, but conflicted with the oncologist. I was then more proactive in my care, and switched specialists.

A survivor with bladder cancer shared,

I did my own research online and then consulted with the members of my list. I knew in my heart that this was not the right treatment for me, not yet anyway, when there was something better out there. The members on my list confirmed my belief and recommended some research to back up their opinions. This gave me the courage to say that I didn't want the treatment and I decided to change physicians.

Endorsement: Participants exercised power through endorsement. Online communities served as a vehicle for endorsing preferred healthcare providers with a proven track record in the diagnosis and treatment of cancer. One survivor with renal cell carcinoma (RCC) explained,

I found the name of an RCC specialist, well-known for her expertise with my subtype of RCC. . . . She has been in the archives for over eight years as an RCC specialist for many on the [online community]. . . . I would not have known of her without the help of this list, nor would I have had the years of others' experience with this specialist.

Participants endorsed healthcare providers who were willing to take the time to answer questions or were inclined to communicate via e-mail. Participants also endorsed specialists from major cancer centers of excellence for superior care and outcomes. One survivor with thyroid cancer illustrated this point and shared, "I learned that there was help for my paralyzed vocal cord, and that it's important to travel to the major cancer centers for treatment. I now have a voice and can speak well above a whisper, which is wonderful."

Discussion

Study participants were highly engaged with the Internet and found online communities to be particularly valuable and often "life saving" during cancer survivorship. Their experiences with healthcare providers illuminated failed expectations and unmet needs in cancer survivorship. Findings converge with past research suggesting that patients' cancer-related information needs often are not met adequately through clinical encounters with healthcare providers (Chen & Siu, 2001; Pereira et al., 2000; Sharf, 1997; Shaw et al., 2007; Ziebland, 2004). Armed with information from the Internet, survivors and caregivers exercised power in healthcare relationships to influence care decisions. In many instances, survivors and caregivers resisted the will of the healthcare provider, such as by changing providers. This finding is consistent with past research in which empowerment emerged as a major construct in the context of the Internet as a source of health information (Broom, 2005b; Brotherton et al., 2002; Dickerson et al., 2006; Pitts, 2004; Sharf, 1997; van Uden-Kraan et al., 2008; Ziebland et al., 2004).

Disenchantment propelled survivors and caregivers to search for information on the Internet; conversely, the Internet revealed inadequacies in survivorship care and precipitated the experience of disenchantment. Disenchantment in healthcare relationships has been experienced by caregivers in the context of chronic illness (Husband, 2001; Sloan, 1999; Thorne & Robinson, 1988, 1989). Disenchantment was distinguished by dissatisfaction related to a lack of informational support, empathy, and hope from healthcare providers (Thorne & Robinson, 1988). The stage of disenchantment was described as a consequence of naive trust that "shattered in the face of unmet expectations and conflicting perspectives between themselves and their professional healthcare providers" (Thorne & Robinson, 1989, p. 154). During the stage of disenchantment, caregivers exhibited aggressive or assertive behaviors (e.g., becoming more informed and knowledgeable) to influence care decisions (Thorne & Robinson, 1988). The finding of disenchantment in the current study supports the validity of Thorne and Robinson's (1988, 1989) model of healthcare relationships in the context of cancer survivorship.

Limitations

The limitations of self-selection sampling bias inherent in survey research and the lack of sociodemographic data are outweighed by the established trustworthiness of the current study and the richness of the data set. Although the transferability of the findings is limited to this sample of ACOR community members, the current study advances nursing knowledge about healthcare relationships and calls attention to failures in cancer survivorship care.

Implications for Nursing

Nurses in professional practice must facilitate therapeutic communication with survivors and caregivers about the use of the Internet as a source of health information and resources and ensure that unmet needs, especially informational support, are addressed in cancer survivorship care plans. Professional nurses possess the foundational competencies of evidence-based practice, technology, leadership, interprofessional collaboration, and communication skills (American Association of Colleges of Nursing [AACN], 2008) to lead and coordinate interdisciplinary programs and models of care that support decision making, self-management, and quality of life in cancer survivorship.

Nurses and other healthcare professionals need education on survivorship issues, including use of the Internet as a source of health information. Use of the Internet and its impact on healthcare relationships during survivorship are considered essential content and must be incorporated into health professions' curricula. Building on *The Essentials of Baccalaureate Education for Professional Nursing Practice* (AACN, 2008), curricula should include virtual learning experiences such as immersion in online communities and moderating online cancer support groups.

Studies exploring the experience of disenchantment and its significance in cancer survivorship are noticeably absent in the extant nursing literature. To grasp the experience of disenchantment, phenomenologic research that describes the lived experience or essence of disenchantment is warranted. Future studies examining the relationship between disenchantment and survivorship outcomes, such as physiologic indicators of health status and quality of life, are recommended.

Conclusions

Disenchantment is experienced as both an antecedent and consequence of Internet information seeking during cancer survivorship. On the basis of knowledge awareness and acquisition through online health information and resources, cancer survivors and caregivers exercise power in their relationship with healthcare

providers to influence care decisions. Theoretical linkages between disenchantment and exercising power cannot be concluded from this qualitative, descriptive research. Nurses in professional practice will be pivotal in addressing cancer survivorship issues of evidence-informed decision making, self-management, and quality of life.

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